



## **END OF LIFE CARE BIBLIOGRAPHY FEBRUARY 2003**

1: Am J Hosp Palliat Care 2003 Jan-Feb;20(1):41-51

Hospice and primary care physicians: attitudes, knowledge, and barriers.

Ogle K, Mavis B, Wang T.

Program in Palliative Care Education and Research, and Department of Family Practice, Michigan State University, East Lansing, Michigan, USA.

Underuse of hospice services is a significant problem in the United States.

Primary care physicians constitute an increasing referral base and have been hypothesized to be important barriers to increased use. We conducted a mail survey of 131 primary care physicians (overall response rate of 72 percent), examining their attitudes toward, knowledge about, and perceived benefits and barriers to hospice care. Physicians demonstrated very favorable attitudes towards hospice. They had correct knowledge about most aspects of hospice, and, where they did not, they were far more likely to be uncertain than erroneous. Primary care physicians perceived many benefits to hospice care and identified patient and family readiness as the major barrier to earlier hospice referrals. A significant subgroup had concerns about problems in interacting with hospices. There were very few differences between family practitioners and general internists. These findings have many implications for directing collaborative efforts between primary care physicians and hospices to improve end-of-life care.

PMID: 12568436 [PubMed - in process]

2: Am J Nurs 2003 Jan;103(1):48-55; quiz 56

Ethical concerns in end-of-life care.

Scanlon C.

Catholic Health Initiatives, 1999 Broadway, Denver, CO 80202, USA.

Publication Types:

Review

Review, Tutorial

PMID: 12544058 [PubMed - indexed for MEDLINE]

3: Aust Fam Physician 2002 Nov;31(11):1036-7

Dying.

Esslemont I.

PMID: 12471964 [PubMed - indexed for MEDLINE]

4: BMJ 2003 Jan 4;326(7379):30-4  
Comment on:  
BMJ. 2003 Jan 4;326(7379):30-4.  
Commentary: a "good death" is possible in the NHS.  
Neuberger RJ.  
King's Fund, London W1M 0AN.  
Publication Types:  
Comment  
PMID: 12516617 [PubMed - indexed for MEDLINE]

5: BMJ 2003 Jan 4;326(7379):30-4  
Comment in:  
BMJ. 2003 Jan 4;326(7379):30-4.  
Care of the dying patient: the last hours or days of life.  
Ellershaw J, Ward C.  
Marie Curie Centre Liverpool, Speke Road, Liverpool L25 8QA.  
jellershaw@mariecurie.org.uk  
Publication Types:  
Review  
Review, Tutorial  
PMID: 12511460 [PubMed - indexed for MEDLINE]

6: Clin J Oncol Nurs 2002 Nov-Dec;6(6):332-6  
Restoring the spirit at the end of life: music as an intervention for oncology nurses.  
Halstead MT, Roscoe ST.  
mhalstead@towson.edu  
Music is a useful therapeutic intervention that can improve quality of life for dying patients. Physiologic mechanisms in response to carefully chosen musical selections help to alleviate pain, anxiety, and nausea and induce sleep. Expression of feelings enhances mood. Palliative care nurses increase the effectiveness of this intervention through careful assessment of patient needs, preferences, goals of intervention, and available resources. Music, a universal language, is an important clinical adjunct that addresses individual and family needs, thereby assisting patients to achieve a peaceful death. This article explores musical categories of preferences to assist nurses, patients, and families in choosing music that meets specific therapeutic objectives.  
PMID: 12434464 [PubMed - indexed for MEDLINE]

7: Comput Inform Nurs 2003 Jan-Feb;21(1):29-36  
Technology Survey of Nursing Programs: Implications for Electronic End-of-Life Teaching Tool Development.  
Wells MJ, Wilkie DJ, Brown MA, Corless IB, Farber SJ, Judge MK, Shannon SE.  
From an online survey of current technological capabilities of US undergraduate nursing programs, we found almost universal use of Microsoft Windows-based computers and Microsoft Office Suite software. Netscape and Microsoft Internet Explorer were the most popular browsers for Internet access. The survey also assessed faculty preferences for end-of-life care teaching materials and found that nurse educators preferred simple easy-to-use tools provided on CD-ROM or the Internet, with instructions provided via CD-ROM, the Internet, and demonstration workshops. Our findings have numerous implications for the

development of electronic teaching materials for nursing.  
PMID: 12544152 [PubMed - as supplied by publisher]

8: Fam Med 2002 Sep;34(8):572-3  
"Mercy"--narrative, role-play, and attitudes concerning antemortem care.  
Jackson WC, Cunningham P.  
Department of Family Medicine, University of Tennessee, Memphis 38019, USA.  
wcjackson@utmem.edu  
PMID: 12269532 [PubMed - indexed for MEDLINE]

9: Gerontologist 2002 Dec;42(6):877; author reply 877-8  
Comment on:  
Gerontologist. 2002 Jun;42(3):342-9.  
Response to "Obstacles to palliation and end-of-life care in a long-term care facility".  
Galanos AN, Moore JD.  
Publication Types:  
Comment  
Letter  
PMID: 12451170 [PubMed - indexed for MEDLINE]

10: Health Serv Res 2002 Dec;37(6):1625-42  
Medical expenditures during the last year of life: findings from the 1992-1996 Medicare current beneficiary survey.  
Hoover DR, Crystal S, Kumar R, Sambamoorthi U, Cantor JC.  
Department of Statistics, Rutgers University, Piscataway, New Jersey 08854-8019, USA.  
OBJECTIVE: To compare medical expenditures for the elderly (65 years old) over the last year of life with those for nonterminal years. DATA SOURCE: From the 1992-1996 Medicare Current Beneficiary Survey (MCBS) data from about ten thousand elderly persons each year. STUDY DESIGN: Medical expenditures for the last year of life and nonterminal years by source of payment and type of care were estimated using robust covariance linear model approaches applied to MCBS data. DATA COLLECTION: The MCBS is a panel survey of a complex weighted multilevel random sample of Medicare beneficiaries. A structured questionnaire is administered at four-month intervals to collect all medical costs by payer and service. Medicare costs are validated by claims records. PRINCIPAL FINDINGS:  
From 1992 to 1996, mean annual medical expenditures (1996 dollars) for persons aged 65 and older were \$37,581 during the last year of life versus \$7,365 for nonterminal years. Mean total last-year-of-life expenditures did not differ greatly by age at death. However, non-Medicare last-year-of-life expenditures were higher and Medicare last-year-of-life expenditures were lower for those dying at older ages. Last-year-of-life expenses constituted 22 percent of all medical, 26 percent of Medicare, 18 percent of all non-Medicare expenditures, and 25 percent of Medicaid expenditures. CONCLUSIONS: While health services delivered near the end of life will continue to consume large portions of medical dollars, the portion paid by non-Medicare sources will likely rise as the population ages. Policies promoting improved allocation of resources for end-of-life care may not affect non-Medicare expenditures, which disproportionately support chronic and custodial care.  
PMID: 12546289 [PubMed - indexed for MEDLINE]

11: Healthcare Benchmarks Qual Improv 2003 Jan;10(1):9-10  
U.S. end-of-life care gets a (barely) passing grade.  
The vast majority of Americans would prefer to die at home. A minority of hospitals offer hospice or palliative care services. Report card enables state-to-state comparisons, benchmarking.  
PMID: 12561127 [PubMed - in process]

12: Int J Palliat Nurs 2002 Nov;8(11):540-7  
Use of quality-of-life scores in care planning in a hospice setting: a comparative study.  
Hill N.  
Mary Potter Hospice, Mein Street, Newtown, Wellington South, New Zealand.  
This study examined the concept and measurement of quality of life (QOL) in terminally ill patients. It also addressed how patients' QOL can be improved within a hospice setting. Measurement of QOL was used in developing patient-care plans and to identify differences in QOL assessment between nurse and patient as an aid to reflective practice. The findings of the study revealed that a better understanding of the patient can be achieved if nurses have access to the patient's QOL perspective. This better understanding, when translated into meeting patients' QOL priorities and needs, resulted in clinically significant improvements in their QOL. Reflective practice by nurses was also shown. A second article will discuss how the theme 'revelation' emerged from the insights of those involved in the study.  
PMID: 12514464 [PubMed - indexed for MEDLINE]

13: Intern Med J 2002 Sep-Oct;32(9-10):435-6  
Comment on:  
Intern Med J. 2002 Sep-Oct;32(9-10):475-80.  
Advance care planning and advance directives: time for action.  
Vinen J.  
Publication Types:  
Comment  
Editorial  
PMID: 12380694 [PubMed - indexed for MEDLINE]

14: Intern Med J 2002 Sep-Oct;32(9-10):475-80  
Comment in:  
Intern Med J. 2002 Sep-Oct;32(9-10):435-6.  
Advance care planning in Australia: overdue for improvement.  
Taylor DM, Cameron PA.  
david.taylor@mh.org.au  
As the population of Australia ages, the issue of advance care planning (ACP) to improve medical management towards life's end becomes more important. However, ACP appears poorly developed in Australia. This article discusses ACP and advance directives in the context of the Australian experience and compares this with the experience overseas. It highlights the need for an improvement in ACP and recommends specific areas for discussion and research.  
PMID: 12380702 [PubMed - indexed for MEDLINE]

15: Issues Law Med 2002 Fall;18(2):111-26  
Dutch perspectives on palliative care in the Netherlands.  
Cohen-Almagor R.

University of Haifa.

This study reports data gathered via extensive interviews with some of the leading authorities on the euthanasia policy that were conducted in the Netherlands. They were asked: It has been argued that the policy and practice of euthanasia in the Netherlands is the result of undeveloped palliative care. What do you think? I also mentioned the fact that there are only a few hospices in the Netherlands. The responses were different and contradictory. Many interviewees agreed with the statement. Almost all of those agreeing with it said that only during the late 1990s were people beginning to admit that there was a need to improve palliative care. Some interviewees insisted that doctors first need to explore other options for helping the patient prior to choosing the course of euthanasia. Other interviewees thought that palliative care is well developed in the Netherlands and that euthanasia has actually paved the way for calling more attention to palliative care.

PMID: 12479156 [PubMed - indexed for MEDLINE]

16: J Am Coll Surg 2002 Dec;195(6):879-87

Is this a bad day, or one of the last days? How to recognize and respond to approaching demise.

Dunn GP, Milch RA.

Great Lakes Home Health Care, Erie, PA, USA.

PMID: 12495320 [PubMed - indexed for MEDLINE]

17: J Am Geriatr Soc 2002 Dec;50(12):2077-83

Managing end-of-life care: comparing the experiences of terminally ill patients in managed care and fee for service.

Slutsman J, Emanuel LL, Fairclough D, Bottorff D, Emanuel EJ.

Department of Health Policy and Management, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland, USA.

There have been no published empirical studies comparing the experiences of terminally ill patients in managed care organizations (MCOs) and those in fee for service (FFS). This investigation represents the first empirical study to systematically compare substantive outcomes between populations of terminally ill patients enrolled in MCO and FFS healthcare delivery systems. The investigators interviewed 988 patients whose physicians judged them to be terminally ill and 893 of their caregivers. Outcomes assessments were made in six domains: patient-physician relationship; access to care and use of health care; prevalence of symptoms; and planning for end-of-life care, care needs, and economic burdens. Overall, the two populations of terminally ill patients were found to have comparable outcomes, but several significant differences were present. MCO patients were more likely than their FFS counterparts to use an inconvenient hospital ( $P = .02$ ), spend more than 10% of their income on medical care ( $P = .02$ ), and have been bedridden more than 50% of the time during the last 4 weeks of life ( $P = .03$ ). Caregivers of MCO patients were as likely as the caregivers of FFS patients to report a substantial caregiving burden ( $P = .59$ ). Despite concerns about the threats of MCOs to the physician-patient relationship, few differences in the quality of the relationship between the two cohorts were found. Finally, terminally ill patients in MCOs did not show better experiences than those in FFS on any outcome measure. Additional research is required to explore how MCOs may improve upon the care available to dying patients.

PMID: 12473022 [PubMed - indexed for MEDLINE]

18: J Am Geriatr Soc 2002 Dec;50(12):2057-61

The effect of do-not-resuscitate orders on physician decision-making.

Beach MC, Morrison RS.

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The effect of do-not-resuscitate (DNR) orders on physicians' decisions to provide life-prolonging treatments other than cardiopulmonary resuscitation (CPR) for patients near the end of life was explored using a cross-sectional mailed survey. Each survey presented three patient scenarios followed by 10 treatment decisions. Participants were residents and attending physicians who were randomly assigned surveys in which all patient scenarios included or did not include a DNR order. Response to three case scenarios when a DNR order was present or absent were measured. Response from 241 of 463 physicians (52%) was received. Physicians agreed or strongly agreed to initiate fewer interventions when a DNR order was present versus absent (4.2 vs 5.0 ( $P = .008$ ) in the first scenario; 6.5 vs 7.1 ( $P = .004$ ) in the second scenario; and 5.7 vs 6.2 ( $P = .037$ ) in the third scenario). In all three scenarios, patients with DNR orders were significantly less likely to be transferred to an intensive care unit, to be intubated, or to receive CPR. In some scenarios, the presence of a DNR order was associated with a decreased willingness to draw blood cultures (91% vs 98%,  $P = .038$ ), central line placement (68% vs 80%,  $P = .030$ ), or blood transfusion (75% vs 87%,  $P = .015$ ). The presence of a DNR order may affect physicians' willingness to order a variety of treatments not related to CPR. Patients with DNR orders may choose to forgo other life-prolonging treatments, but physicians should elicit additional information about patients' treatment goals to inform these decisions.

PMID: 12473020 [PubMed - indexed for MEDLINE]

19: J Cancer Educ 2002 Summer;17(2):92-6

Technology available in nursing programs: implications for developing virtual end-of-life educational tools.

Wells MJ, Wilkie DJ, Brown MA, Corless IB, Farber SJ, Judge MK, Shannon SE. University of Washington School of Nursing, Seattle 98195, USA.

**BACKGROUND:** To overcome insufficient attention to end-of-life (EOL) care in nursing education, the authors are developing the "Toolkit for Nursing Excellence at End-of-Life Transition" (TNEEL). **METHOD:** An evidence-based design process was used to create a computerized (CD-ROM) multimedia toolkit of instructional aides. An online survey of all U.S. undergraduate nursing programs was conducted to identify their current technologic infrastructures available for innovative teaching aides. Expert review process guided pedagogic decisions. **RESULTS:** Survey findings enabled TNEEL development to be responsive to nurse educators' needs and preferences. **CONCLUSION:** Educators can use TNEEL to actively engage students in meaningful learning about EOL care.

PMID: 12092860 [PubMed - indexed for MEDLINE]

20: J Emerg Nurs 2002 Dec;28(6):515-22

Terminally ill patients in the emergency department: a practical overview of end-of-life issues.

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Emergency Services, Marlborough Hospital, Marlborough, Mass., USA.

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Publication Types:



Review  
Review, Tutorial  
PMID: 12509728 [PubMed - indexed for MEDLINE]

21: J Nurs Res 2002 Sep;10(3):161-7

Physicians attitudes toward DNR of terminally ill cancer patients in Taiwan.

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The purpose of this study was to survey physicians' attitudes toward DNR of terminally ill cancer patients in Taiwan. A total of 7626 structured questionnaires were sent by mail to physicians who were members of the Taiwan Society of Internal Medicine and the Surgical Association of Taiwan, and 1328 valid responses were received. The response rate was 17.6%. The instrument, a structured questionnaire, was composed of one scenario and six questions. A majority (77.6%) of the physicians under investigation would tell a terminally ill cancer patient or his family about the possibility of DNR and ask them to consider signing a consent form. Over one half of the physicians (58.4%) did not know whether the Medical Law in Taiwan permits natural death, and 96.1% of the subjects felt they would need legal protection for agreeing patient's autonomy to decide DNR. Unfortunately, 41.2% of the respondent admitted that they did not have a formal Informed Consent Form that could be used for DNR. Even of those who had such a form, only 27.4% had clear guidelines given by their institutions. Among 623 physicians whose institutions had an formal Informed Consent Form for DNR, 63.7% agreed that it was reasonably used. Surprisingly, 67.9% of the physicians had used Slow Codes. The findings of this study served as a solid base. The investigator and other colleagues used it to convince legislators to pass a Natural Death Act in Taiwan. Since some legislators disliked the term death and the main promotes were people engaged in hospice palliative care, the new law entitled Hospice Palliative Act was passed on May 23, 2000. The DNR order finally gained its legal base for medical practice. The limitation of this study was the low response rate. However, since the subjects, physicians, had a busy work load, this was still an acceptable response rate.  
PMID: 12244518 [PubMed - indexed for MEDLINE]

22: J Pain Symptom Manage 2002 Dec;24(6):616-20

A Clear View from One Side of the Looking Glass. The Case Against Assisted Suicide: For the Right to End-of-Life Care Edited by Kathleen Foley and Herbert Hendin Published by The Johns Hopkins University Press, Baltimore, 2002 392 pages, \$49.95.

Quill TE.

Timothy E. Quill, MD is Professor of Medicine, Psychiatry, and Medical Humanities at the University of Rochester School of Medicine, Rochester, NY, USA  
PMID: 12551813 [PubMed - in process]

23: J Pain Symptom Manage 2002 Nov;24(5):459-70

Understanding the continuum of palliative care for patients and their caregivers.

Yurk R, Morgan D, Franey S, Stebner JB, Lansky D.

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We describe a process for assisting seriously ill patients and their caregivers

in prioritizing their preferences for care during advanced illness. Thirty-two seriously ill patients and their caregivers participated in seven 90-minute focus groups conducted cross-sectionally in Denver, Colorado; San Francisco, California; and Washington State. Fourteen expert-defined end-of-life quality indicators were presented to each group, and quantitative unweighted rankings were obtained through patient and caregiver preferences. Aggregated weightings were used to rank the top five quality measures for exploration of open-ended questions. Pain management was the most important quality indicator among all three groups. Overlap in preferences were found for at least two of the groups for symptom management, monitoring medical issues, advance care preferences and assessment of family and caregiver involvement. Caregivers were more focused on bereavement support. Variation in preferences for end-of-life care by patients and their caregivers reflects the need to understand the individual decision-making regarding end-of-life care. Quality improvement activities are beginning to address these needs.  
PMID: 12547046 [PubMed - in process]

24: J Pain Symptom Manage 2002 Oct;24(4):447-53

Definition of sedation for symptom relief: a systematic literature review and a proposal of operational criteria.

Morita T, Tsuneto S, Shima Y.

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Although sedation for symptom relief in terminally ill patients has been the focus of recent medical studies, the interpretation of research findings is difficult due to the confusing terminology. To clarify the agreements and inconsistencies in the definitions of sedation, a systematic review was performed. We searched the literature through MEDLINE from 1990 to July 2001. A total of 7 articles met the inclusion criteria. All studies included the use of sedative medications or the intention to reduce patient consciousness as an essential element of sedation. All but one study explicitly described that the primary aim of sedation was symptom palliation. Three definitions stated that target symptoms were severe, and 4 articles reported the refractory nature of the distress. On the other hand, there were marked inconsistencies in the definition of the degree of sedation, duration, pharmacological properties of medications used, target symptoms, and target populations. This review suggests that sedation includes two core factors: the presence of severe suffering refractory to standard palliative management, and the use of sedative medications with the primary aim to relieve distress. Thus, "palliative sedation therapy" can be defined as "the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness." The marked inconsistencies in the definition of sedation should be considered to be subcategories of palliative sedation therapy, and we recommend that researchers define the degree of sedation, duration, pharmacological properties of medications, target symptoms, and target populations in future studies. This clarification of terminology will contribute to improving the accuracy and depth of sedation research.

Publication Types:

Review

Review, Tutorial

PMID: 12505214 [PubMed - indexed for MEDLINE]



25: J Pain Symptom Manage 2002 Oct;24(4):388-97

Quality of life of palliative care patients in the last two weeks of life.

Lo RS, Woo J, Zhoc KC, Li CY, Yeo W, Johnson P, Mak Y, Lee J.

Palliative Care Unit, Department of Medicine and Geriatrics, Shatin Hospital, 33-A Kung Kok Street, Ma On Shan, New Territories, Hong Kong.

Quality of life (QOL) is the main consideration in caring for advanced cancer patients, yet little is known about the QOL in the terminal phase. We profiled the QOL of 58 advanced cancer patients during their last 2 weeks of life using the McGill QOL questionnaire-Hong Kong version. The patients provided ratings of QOL an average of 5.6 (median 6) days pre-death. Palliative care services were successful in maintaining the total QOL score during the dying phase. The mean score was 7.0 of 10. Among the various domains, the physical and existential domains scored relatively poorly at 5.9 and 6 of 10, respectively. The worst physical symptom and meaning of life were the individual items with the poorest scores (4.8 and 5.4 of 10, respectively). Compared with admission, there was statistically significant improvement in the worst physical symptom ( $P = 0.02$ ) and eating item ( $P = 0.002$ ), but deterioration in physical well-being ( $P = 0.03$ ), meaning of existence ( $P = 0.007$ ), and satisfaction with oneself ( $P = 0.04$ ). In conclusion, QOL evaluation during the terminal phase identifies important aspects requiring improvement during the last two weeks of life. Physical and existential domains of dying cancer patients needed more attention. PMID: 12505207 [PubMed - indexed for MEDLINE]

26: J Pain Symptom Manage 2002 Oct;24(4):398-403

Care of the dying: is pain control compromised or enhanced by continuation of the fentanyl transdermal patch in the dying phase?

Ellershaw JE, Kinder C, Aldridge J, Allison M, Smith JC.

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The introduction of fentanyl transdermal patches has led to concern and confusion regarding the management of pain control in the dying phase. Data were collected retrospectively from 94 dying patients. Two groups were identified-patients treated with fentanyl transdermal patch who remained on the patch in the dying phase and patients on oral morphine who converted to a 24-hour subcutaneous infusion of diamorphine via a syringe driver in the dying phase. Both the fentanyl group and the diamorphine group had good pain control in the last 48 hours of life. During the last 48 hours of life, the proportion of patients with controlled pain was statistically significant in favor of the fentanyl group in 2 of the 12 observations undertaken, in particular whether the fentanyl transdermal patch should be continued or discontinued. Patients in the fentanyl group received fewer "as required" opioid doses compared to patients in the diamorphine group, although the difference was statistically significant only for the last day of life. This study showed that pain control was not compromised in the dying phase with continued use of the fentanyl patch. PMID: 12505208 [PubMed - indexed for MEDLINE]

27: J Palliat Med 2002 Oct;5(5):754-5

Volunteer patient advocacy: an interdisciplinary course on attending to patients at the end of life.

Rabow MW, Petersen JJ, Schanche K.

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Little is known about the impact on health care students of early end-of-life

care (EOLC) education and patient contact. We developed an EOLC course that allowed students to serve as volunteer advocates for patients at the end of life (EOL). We evaluated the course's acceptability to students and its effect on students' attitudes and beliefs.

PMID: 12572979 [PubMed - in process]

28: J Palliat Med 2002 Oct;5(5):705-12

Age and gender differences in health care utilization and spending for medicare beneficiaries in their last years of life.

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Men's and women's health care experiences differ as they age. While increasing attention has been focused on gender differences in health status, prevalence of illnesses, and access to quality care among older adults, little is known about differences in their health care in the last years of their lives. This paper uses claims data for a 0.1% random sample of Medicare beneficiaries who died between January 1, 1994 and December 31, 1998 to assess age and gender differences among Medicare-eligible adults in their utilization of health care services in the last year of life. Overall, age is much more important than gender in explaining most of the variation in end-of-life care. The combination of being a Medicare beneficiary and being sick enough to die appears to attenuate gender disparities in health care services utilization.

PMID: 12572969 [PubMed - in process]

29: J Palliat Med 2002 Oct;5(5):729-37

End-of-life care for terminally ill participants in clinical research.

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Efforts to improve end-of-life care in the United States have paid little attention to the unique concerns of participants in clinical research who are terminally ill. In this paper we focus attention on and offer an analysis of how to meet the needs of these individuals. To address their concerns, we consider how to reconcile two important tasks: providing optimal end-of-life care and conducting clinical research. First, we examine the inherent tension between the goals of medicine and the goals of science. Second, we focus more specifically on the tensions between a good death and conducting clinical research in patients with a short life expectancy. We examine six domains that have been suggested for measuring a good death: physical symptoms; psychological and cognitive symptoms; economic and caregiving needs; social relationships; spiritual beliefs; hopes and expectations. For each of these domains we examine how the goals of clinical research may conflict or coincide with taking care of a patient with a terminal illness. Finally, we offer suggestions to address these tensions: (1) modify the informed consent discussion for terminally ill participants in research; (2) build a palliative care component into clinical trials; (3) attend to the needs of family caregivers of terminally ill research subjects; (4) arrange for continuity of care so that dropping out of a trial does not jeopardize medical care; (5) train clinical investigators in end-of-life care; (6) develop a counseling strategy for terminally ill participants in clinical research.

PMID: 12572972 [PubMed - in process]

30: J Psychosom Obstet Gynaecol 2002 Jun;23(2):73-5  
Euthanasia--or, death on request.  
Heintz AP.  
Publication Types:  
Editorial  
PMID: 12189899 [PubMed - indexed for MEDLINE]

31: J Psychosom Obstet Gynaecol 2002 Jun;23(2):77-82  
Comment in:  
J Psychosom Obstet Gynaecol. 2002 Dec;23(4):267-9.  
A time to be born and a time to die: reflections on euthanasia.  
Schuiling GA.  
Division of Human Biology, Faculty of Medical Sciences, University of Groningen, A. Deusinglaan 1, 9713 AV Groningen, The Netherlands. g.a.schuiling@med.rug.nl  
Euthanasia is, and probably will remain a controversial issue. Although many doctors will agree that under certain circumstances a demand for euthanasia should be granted (and in fact often is granted when the occasion arises), the subject generally gives rise to very emotional debates. Attempts to decriminalize euthanasia generally fail, and this contrasts sharply with the attitude of many towards issues like capital punishment and the objectives of, for example, the military. In this essay this apparent contradiction is discussed from the evolutionary biological point of view. It is argued that euthanasia always concerns the death of a member of some 'in-group' (which in some way we regard as part of ourselves), while capital punishment and the death of (political) enemies always concerns the death of members of some 'out-group'. It is inherent in our genetic make-up, evolved over millions of years, that we oppose the death of members of in-groups and are indifferent to (even promote) the death of members of out-groups. Attempts to regulate these inclinations by cultural and religious wisdom or commands ('[there is] a time to be born and a time to die' and 'love thy enemies like thyself') are only marginally successful, because biological urges generally dominate cultural notions.  
Publication Types:  
Review  
Review, Tutorial  
PMID: 12189900 [PubMed - indexed for MEDLINE]

32: Med Educ 2003 Jan;37(1):51-8  
Early clinical exposure to people who are dying: learning to care at the end of life.  
MacLeod RD, Parkin C, Pullon S, Robertson G.  
1Mary Potter Hospice, Wellington, New Zealand 2Department of General Practice, Wellington School of Medicine and Health Sciences, University of Otago, Wellington, New Zealand.  
BACKGROUND: The nature of medical care at the end of life and, in particular, the way in which caring is learned remain problematic for medical educators and the profession. Recent work has indicated that doctors learn to care, in an emotional and intimate way, from people who are dying. METHODS: This paper reports on the development of a programme designed for medical students in their first clinical year who spend time with a person who is dying and their family. The students are required to produce a portfolio assignment that includes a personal reflection of the experience. The findings from a phenomenological study undertaken using these personal reflections are reported. These reflections and comments are interpreted as being embedded in five key themes.

RESULTS: The actual encounters differed from the medical students' anticipation of them. Students identified an emotional component to the experience; they explored their own and the patient's understandings of spirituality; they reflected on personal meanings of the encounter and they suggested ways in which they might learn to care more effectively for people who are dying.

DISCUSSION:

The way in which many of these students approach end-of-life care has been altered through a transformative educational experience that encouraged them to draw on their own experiences and skills. Their learning was facilitated by the writing of accounts and the discussion that each group held with teaching staff at the conclusion of the programme.

PMID: 12535115 [PubMed - in process]

33: Mo Med 2002 Nov-Dec;99(10):571-6

Spirituality and end-of-life care.

Shannon SE, Tatum P.

Department of Family and Community Medicine, University of Missouri-Columbia, USA.

As dying patients adjust to the irreversible nature of their illness, their needs and focus of care changes. Spiritual issues may become a central concern for them, and addressing these issues can be key to relieving suffering.

Physicians, unfortunately, have little training in this area and are often uncomfortable discussing spirituality. In this article, we address the role of spirituality in end-of-life care, and discuss a format for spiritual assessment.

We hope this will encourage more comprehensive patient-centered, end-of-life care.

PMID: 12534145 [PubMed - in process]

34: Mo Med 2002 Nov-Dec;99(10):522-3

The endless challenges of end-of-life care.

Fleming DA.

Publication Types:

Editorial

PMID: 12534137 [PubMed - in process]

35: Nurs Manage 2003 Jan;34(1):30-3

Uniting to improve end-of-life care.

Rushton CH, Sabatier K, Gaines J.

Survey results measure the impact of a national invitational nursing conference on end-of-life care.

PMID: 12544580 [PubMed - in process]

36: Nurs Times 2002 Dec 10-16;98(50):39-41

Patient preferences for a single or shared room in a hospice.

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This study considers the preferences of hospice patients in relation to whether they would like to stay in a single or a shared bedroom and what factors might affect those preferences. It takes note of the circumstances that are likely to be found in a hospice in relation to difficult symptoms such as diarrhoea, the process of dying and noise from other patients. The findings show that patients generally have a preference for single rooms in order to preserve their dignity, respect and privacy. It also shows that choice is important and that a number of

shared rooms will always be required for patients who prefer to have company.  
PMID: 12518551 [PubMed - indexed for MEDLINE]

37: Nurse Educ 2003 Jan-Feb;28(1):40-3

Achieving Excellence in End-of-Life Care.

Pimple C, Schmidt L, Tidwell S.

Nurses in practice have verified the need for nursing education curricula to include content related to care of the dying patient. Nurse educators are initiating curricular changes to assure students have the knowledge and attitudes needed to provide quality care at the end of life. The authors discuss one university undergraduate program's development of both a theory and practicum course.

PMID: 12544616 [PubMed - in process]

38: Nursing 2002 Nov;32(11 Pt 1):50-2

Roy's choice.

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PMID: 12441857 [PubMed - indexed for MEDLINE]

39: Omega (Westport) 2001;43(4):349-61

End of life care and reactions to death in African-American and white family caregivers of relatives with Alzheimer's disease.

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Family caregivers for relatives with Alzheimer's Disease (AD) often experience significant stress-related problems in mental and physical health. Patients with AD often survive for protracted periods of time, placing an extensive burden of care on the caregiver prior to the patient's death. The present study addresses ethnic differences in the experience of AD caregivers around the time of their loved one's death, including life-sustaining treatment decisions and reactions to death. The results showed that, in our sample, more patients died in their homes than has been reported for deaths in the United States. African-American and White caregivers differed substantially in their reports of end of life care and subjective reactions to the death. Compared with White caregivers, African-American caregivers were less likely to make a decision to withhold treatment at the time of death, less likely to have their relative die in a nursing home, and reported less acceptance of the relative's death and greater perceived loss. Results suggest that death after AD caregiving deserves further study, and that ethnic differences in end of life care and bereavement may be of particular importance.

PMID: 12569925 [PubMed - in process]

40: Omega (Westport) 2000;42(4):273-91

Planning end-of-life care for patients with dementia: roles of families and health professionals.

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We examined families' end-of-life decision making and their interactions with health professionals. Twenty-eight family members of institutionalized dementia patients participated in four focus groups. We found that participating family members were not well prepared for their decision-making roles, and that they:

1) experienced substantial burdens and loss in caring for institutionalized elders; 2) had limited understanding of the natural progression of dementing conditions; 3) were uncomfortable in setting goals for their relatives' end-of-life care; 4) had little experience with death, and were ambivalent about the anticipated death of their relative; and (5) reported that they had little substantive communication with health professionals regarding end-of-life care planning. We concluded that many of the needs of such families could be addressed through improved application of the principles of advance care planning, including regular structured discussions, involvement of surrogate decision-makers, and anticipation of clinical decisions. Health professionals should take the lead in 'normalizing' the discussion of death.  
PMID: 12569923 [PubMed - in process]

41: Omega (Westport) 2000;41(3):157-85

False expectations? Expectations vs. probabilities for dying.

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It is widely recognized that the code of the physician has undergone dramatic changes in the last century--changes which have serious implications for the patient-physician relationship. This is an ethnographic study examining how certain changes in the role and abilities of biomedical physicians have affected patient attitudes and expectations about end-of-life care. In-home interviews were conducted with eighteen persons age fifty-five and older, including a sample of Hemlock Society members. Results indicate a broad spectrum of end-of-life concerns including capacity, autonomy, pain, and burden to loved ones. Most participants reported a reluctance to begin a discussion of death or future deteriorating capacity with their physicians. Instead, when conversations about death were reported, they had been largely limited to the scenarios of catastrophic illness (e.g., hospitalization, ventilator, etc.) and the Living Will. While this discussion does not overlook the utility of the Living Will, it proposes the reliance on this document for preparing patients for end-of-life care is inadequate.

PMID: 12557883 [PubMed - in process]

42: Oncol Nurs Forum 2002 Nov-Dec;29(10):1421-8

Symptom distress and quality of life in patients with cancer newly admitted to hospice home care.

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PURPOSE/OBJECTIVES: To evaluate the relationships between quality of life (QOL) and symptom distress, pain intensity, dyspnea intensity, and constipation intensity in people with advanced cancer who were newly admitted to hospice home care. DESIGN: Descriptive and correlational. SETTING: A large hospice that provides primarily home care. SAMPLE: 178 adult hospice homecare patients with cancer who were accrued to a clinical trial funded by the National Institutes of Health focusing on symptom management and QOL. Patients were excluded if they received a score lower than seven on the Short Portable Mental Status Questionnaire. METHOD: The patients were invited to participate in the clinical trial within 48 hours of admission to hospice home care. Among the questionnaires they completed were a QOL index and a distress scale. Scales measuring present intensity of pain, dyspnea, and constipation also were



administered. MAIN RESEARCH VARIABLES: QOL, symptom distress, pain intensity, dyspnea intensity, and constipation intensity. FINDINGS: The most frequently reported symptoms among the sample were lack of energy, pain, dry mouth, and shortness of breath. Lack of energy caused the greatest distress, followed closely by dry mouth and pain. The results of the regression analysis indicated that total distress score, pain intensity, dyspnea intensity, and constipation intensity were related to QOL at the univariate level. When all predictors were considered simultaneously, only the total distress score remained a significant predictor of QOL ( $p < 0.001$ ), accounting for about 35% of variance. CONCLUSIONS:

QOL was affected by symptom distress in people with advanced cancer near the end of life. IMPLICATIONS FOR NURSING: The symptoms most commonly reported and those that cause the greatest patient distress should be addressed first by hospice nurses. Continued effort is needed in the important area of symptom management.

Publication Types:

Clinical Trial

PMID: 12432413 [PubMed - indexed for MEDLINE]

43: Oncology (Huntingt) 2002 Jun;16(6):745-50; discussion 750, 755, 758-60  
Treatment of dyspnea in cancer patients.

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Dyspnea is defined as a sensation of difficult or uncomfortable breathing. The symptom is highly prevalent among cancer patients with and without direct lung involvement. The gold standard of assessment is based on patient self-report. Objective measures such as respiratory rate, oxygen saturation, and arterial blood gas measurements frequently do not correlate with the subjective experience of dyspnea. Consistent with patient goals and the disease context, treatment should be directed at removing the underlying cause when possible. Fast, safe, and effective symptomatic relief of dyspnea is possible whether or not identifiable reversible causes exist. In fact, relieving symptoms can be considered in conjunction with treating specific reversible causes. Opioids are the first-line therapy for relief of dyspnea symptoms. When prescribed appropriately, respiratory depression is not a significant concern. In the rare cases in which opioids are unable to control dyspnea, sedation is an effective, ethical, and legal option.

Publication Types:

Review

Review, Tutorial

PMID: 12088297 [PubMed - indexed for MEDLINE]

44: Oncology (Huntingt) 2002 Jun;16(6):801-8; discussion 808, 811-2

The health economics of palliative care.

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Only a few studies have assessed the economic outcomes of palliative therapy. The major areas of interest include hospice care, the process and structure of care, symptom management, and palliative chemotherapy compared to best supportive care. Compared with nonhospice care, hospice care saves at best 3% of total care costs. Advance directives done early in the disease course may save

end-of-life care costs, but when done in the hospital do not save money or influence care choices. Nurse coordination of palliative care maintained clinical outcomes of dying patients and saved 40% of costs. A structured ethics review of those likely to die in the intensive care unit also appears to match the type of care to the outcome, and save costs. There are remarkably few randomized clinical trials of pain and symptom control interventions in end-of-life care, so few conclusions can be drawn about current treatments. There are no examples of chemotherapy that save money compared to best supportive care. Current data suggest that changes in palliative care cost can only come from dramatic changes in how we provide care. One model is coordinated, expert, high-volume care that can prevent end-of-life hospitalization, with early use of advance directives. Preliminary data from our program support the hypothesis that costs may be reduced by 40% to 70%.

Publication Types:

Review

Review, Tutorial

PMID: 12088300 [PubMed - indexed for MEDLINE]

45: Palliat Med 2002 Nov;16(6):481-7

The provision of palliative care in nursing homes and residential care homes: a survey of clinical nurse specialist work.

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The provision of end-of-life care within nursing and residential care homes is of concern to policy makers and specialist palliative care providers. There is evidence of an increasing number of initiatives involving clinical nurse specialists (CNS) with the care of residents within these care settings, but the extent to which this is occurring in the UK has not been documented. A survey of 730 community CNS in palliative care was undertaken to describe the extent to which these practitioners are involved with the care of residents in nursing and residential care homes and the nature of this work. Although 92% of the CNS surveyed had worked with nursing homes and 80% of the CNS with residential care homes, the responses showed that this work was primarily reactive and undertaken infrequently. The majority of the work undertaken by CNS involved caring for patients with malignant conditions with a clinical focus addressing the management of physical symptoms.

PMID: 12465694 [PubMed - indexed for MEDLINE]

46: Palliat Med 2002 Nov;16(6):465-80

Analyses of nursing home residents in hospice care using the minimum data set.

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OBJECTIVE: To present comprehensive profiles of residents in hospice care at admission to the nursing home using the Minimum Data Set (MDS). DESIGN AND SETTING: We analysed 40,622 MDS admission assessments for nursing home residents in hospice care. The MDS contains resident-focused data on pain, cognitive patterns, physical function, disease diagnoses, medications, nutrition, and specific treatments received. RESULTS: About four in five recently admitted hospice residents had 'do not resuscitate' orders and only 27% had a living will. Over 70% of recently admitted hospice residents experienced pain, with

almost one half experiencing daily pain. Over one half of those hospice residents in pain experienced moderate pain and almost one third experienced horrible or excruciating pain. About 57% of recently admitted hospice patients had cancer, 21 % had congestive heart failure, 20% had emphysema/chronic obstructive pulmonary disease, and 18% had depression. About one in two recently admitted hospice residents exhibited at least moderate impairment in cognitive function. CONCLUSIONS: There is a need to improve pain management, advanced directives, and mental health services for residents dying in nursing homes.

PMID: 12465693 [PubMed - indexed for MEDLINE]

47: Palliat Med 2002 Nov;16(6):542-3

Artificial hydration during the last week of life in patients dying in a district general hospital.

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PMID: 12465704 [PubMed - indexed for MEDLINE]